



June 11, 2021

Senator Bob Casey
393 Russell Senate Office Building
Washington, DC 20510

Senator Joni Ernst
135 Hart Senate Office Building
Washington, DC 20510

Representative Jim McGovern
408 Cannon House Office Building
Washington, DC 20515

Representative Jaime Herrera Beutler
1107 Longworth House Office Building
Washington, DC 20515

Dear Senators Casey and Ernst and Representatives McGovern and Herrera Beutler,

On behalf of Patients & Providers for Medical Nutrition Equity, a coalition of more than 40 patient and provider organizations that represent individuals for whom specialized nutrition is medically necessary for treatment of their digestive or inherited metabolic disorder, we write to provide our strong endorsement of the *Medical Nutrition Equity Act* (S. 2013/H.R. 3783) as re-introduced in the 117th Congress. We applaud your leadership in recognizing the problems that patients with these chronic conditions face, and for introducing legislation that allows these patients and their physicians to pick the treatments that are medically appropriate for them.

Thousands of children and adults in our country live with digestive or inherited metabolic disorders that inhibit their bodies from digesting or metabolizing the food they need to survive. When these conditions are left untreated, food can become toxic or the body can fail to absorb necessary nutrients. These individuals must turn to medically necessary nutrition, such as highly specialized formulas, both as a treatment for their condition and as sustenance.

When diseases of the digestive system or inherited metabolic disorders are left unmanaged or untreated, the medical consequences are often significant, permanent, and costly. The implications of denied or delayed access to medical nutrition in pediatric populations are particularly profound — inadequate growth, abnormal development, cognitive impairment, and behavioral disorders. In severe cases, without medical nutrition, the outcome can be unnecessary surgery, repeated hospitalizations, intellectual disability, or even death. Children with an unmanaged disease also suffer emotionally and socially.

Medically necessary nutrition typically must be ordered through a pharmacy and costs 4-5 times the cost of “normal” food. While this cost puts significant strain on families in the best of times, the cost burden has worsened for many throughout the COVID-19 pandemic.

Additionally, thanks to Congress, nearly four million newborns in the United States receive state-mandated testing for inborn errors of metabolism as recommended by the Secretary of HHS’ Recommended Uniform Screening Panel. Approximately 2,000 of these babies are diagnosed with inherited metabolic disorders as a result of this mandated testing. For most of these babies, the use of medical nutrition is a necessity.

Medically necessary nutrition is sometimes the best or only treatment for a digestive or metabolic condition. Insurance companies will typically cover pharmaceuticals or biologics for treatment of a digestive or metabolic condition. However, these types of treatments are often used off-label or may not be recommended by the treating physician as first-line therapy. Further, pharmaceuticals and biologics are often costly and can have undesirable risks such as cancer or suppression of the immune system, which can increase a patient’s risk of infection.

Even when an insurance company does cover medically necessary nutrition, it often comes with the stipulation the formula be administered through a feeding tube (for example, a nasogastric tube, placed through the nose

into the stomach or a gastrostomy tube, surgically placed directly into the stomach). Surgery to place a feeding tube is expensive and these tubes carry additional risks. For example, a gastrostomy tube can leak, cause ulcerations, or cause infection at the insertion site. In severe cases, a patient may experience a perforation in the intestinal tract. Medically necessary nutrition, when administered under a physician's order, constitutes life-saving treatment with lower costs and fewer risks.

These types of coverage policies are irrational and interfere with thoughtful medical decision making. Further, without coverage, medically necessary nutrition is unaffordable for many families. For example, some children with Crohn's disease require a pre-digested formula such as Peptamen 1.5, which, at five cans per day, can cost an average of \$1,500/month. For many patients and their families, the out-of-pocket costs for specialized formulas are prohibitive, particularly when you consider these formulas cost less than biologics that are covered for some of these conditions.

Your legislation would ensure coverage parity, providing patients the ability to choose the best treatment option in consultation with their physician. Passage of this bill will have a profound effect on the many patients who require medically necessary nutrition to survive and thrive. The Patients & Providers for Medical Nutrition Equity (PPMNE) Coalition thanks you for your critical leadership on this important issue and looks forward to working with you to get the bill passed before the end of the 117th Congress. Please contact Megan Gordon Don at 202.246.8095 or mgdon@mgdstrategies.com if you have any questions or need more information.

Sincerely,

American Academy of Pediatrics
American College of Gastroenterology
American College of Medical Genetics and Genomics
American Gastroenterological Association
American Partnership for Eosinophilic Disorders
American Society for Parenteral and Enteral Nutrition (ASPEN)
Ann & Robert H. Lurie Children's Hospital of Chicago
Association for Creatine Deficiencies
Association of Pediatric Gastroenterology and Nutrition Nurses
Children's Hospital at Dartmouth
Children's Hospital Colorado
Children's Hospital of Wisconsin
Children's Medical Nutrition Alliance
Children's MAGIC US
Children's National Health System
Crohn's & Colitis Foundation
Campaign Urging Research for Eosinophilic Disease (CURED)
CPNP – NASPGHAN Council for Pediatric Nutrition Professionals
EveryLife Foundation for Rare Diseases
FOD (Fatty Oxidation Disorders) Family Support Group
FPIES Foundation
Galactosemia Foundation

Genetic Metabolic Dietitians International (GMDI)
Global Liver Institute
HCU Network America
International Foundation for Gastrointestinal Disorders (IFFGD)
International FPIES Association
Maple Syrup Urine Disease Family Support Group
March of Dimes
National Organization for Rare Disorders (NORD)
National PKU Alliance, Inc.
National PKU News
National Urea Cycle Disorders Foundation
Nationwide Children's Hospital
Network of Tyrosinemia Advocates (NOTA)
North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN)
Oley Foundation
Organic Acidemia Association
Pediatric IBD Foundation
Propionic Acidemia Foundation
Society for Inherited Metabolic Disorders
United Mitochondrial Disease Foundation